



Fighting To End The Tragedy of SIDS
for Brian - 6/01/04 - 9/28/04

Sudden Infant Death Services of the Mid-Atlantic
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Annual Report 2009



Joseph Kimmitt Rainey

March 11 to November 15 1996

*SIDS Celebration of Remembrance at
Arlington Unitarian Universalist Church*

**SIDS Mid-Atlantic held its annual Celebration of Remembrance Sunday, November 8,
at The Arlington Unitarian Universalist Church, Arlington, Virginia.**

**In the rising of the sun and its going down,
We Remember Them.
In the blowing of the wind and the chill of winter,
We Remember Them.
In the opening of the buds and in the rebirth of spring,
We Remember Them.
In the blueness of the skies and in the warmth of summer,
We Remember Them.
In the rustling of the leaves and in the beauty of autumn,
We Remember Them.
In the beginning of the year and when it ends,
We Remember Them.
When we are weary and in need of strength,
We Remember Them.
When we are lost and sick of heart,
We Remember Them.
When we have joys and special celebrations we yearn to share,
We Remember them
So long as we live, they too shall live,
for they are part of us.
We Remember Them**

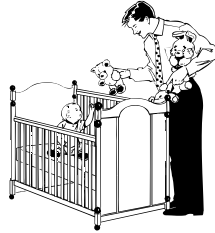


The mission of SIDS Mid-Atlantic is:

**To support family members and others who have been affected by the tragedy of a sudden infant death
To provide education and outreach to help reduce infant deaths**

We provide support to bereaved families with peer support, support groups, newsletters, website, referrals, and family events.

We educate first responders, police, medical and nursing personnel, medical examiners, and funeral home and cemetery personnel about helping families who have lost an infant to SIDS or other infant death. We also educate parents, the medical community, childcare providers, and others, about reducing the risk of SIDS, improving infant safety and reducing infant mortality.



The “Cribs for Kids” Project provides portable cribs to needy families, to reduce the risk of babies dying in unsafe beds. We donated 904 cribs to needy families in 2009.

“Stop Smoking Stop SIDS” provides training on the Five A’s Method of smoking cessation counseling for health care providers and support and encouragement to quit smoking for pregnant and parenting smokers.



Peer Support

SIDS Mid-Atlantic recruits and offers training to interested members of the SIDS community who wish to become peer contacts for newly bereaved parents, siblings and caregivers. Peer support is available by telephone or in person. Peer support offers families comfort and information that only another family who has lost a baby can provide. Families receiving peer support are also given a copy of the book “A SIDS Survival Guide”, a memory book for their baby, booklets on Grandparents Grief, and additional bereavement materials including the SIDS Mid-Atlantic Bereavement Booklet.

Bereavement Booklet

The SIDS Mid-Atlantic Bereavement Booklet covers the following topics, and is provided to newly bereaved families and bereavement counselors, and is downloadable from the SIDS Mid-Atlantic website, www.sidsma.org:

Sudden Infant Death Syndrome

- **Risk Factors**
- **Causes**
- **How Many Babies Die from SIDS**
- **Diagnosis**
- **Autopsy**
- **Death Scene Investigation**

- Review of Victim and Family History
- Helping Bereaved Parents: Do's and Don'ts
- Myths of Grief
- Taking Care of Yourself
- Strategies to Help Survive Painful Times
- Caring for Surviving Children
- Children's Understanding of Death
- Grief of Grandparents
- Subsequent Children
- After SIDS
- You Are Not alone
- Anniversaries, Holidays and Special Events
- Support Groups and Community Resources for Grief and Loss
- When SIDS Occurs in Child Care Settings
- A Loving Goodbye
- Planning the Service
- Choosing the Funeral Home
- Choosing the Cemetery
- Helping Children Through the Funeral Process

Support Group Meetings

SIDS Mid-Atlantic facilitates support groups for anyone affected by an infant death. All support groups and peer contact services are free of charge.

Support groups meet monthly at the McLean Presbyterian Church, and are facilitated by a Licensed Clinical Social Worker who is an expert on bereavement and grief counseling. Emotional support as well as information on returning to work, helping their surviving children grieve, communication with one's spouse, planning a subsequent pregnancy, and coping with anniversaries, birthdays and holidays are some of the services provided. We held 12 support group meetings in 2009.

Newsletter and website

SIDS Mid-Atlantic produces a newsletter for SIDS families, "*The Family Connection*" and a website www.sidsma.org

The newsletter, "*The Family Connection*" provides information on activities, support groups, and resources relating to bereavement. "*The Family Connection*" newsletter is distributed to 500 homes in the region and electronic copies are sent to over 2000 health professionals.

The website provides bereavement information and resources including The SIDS Mid-Atlantic Bereavement Booklet. The website also offers information on SIDS and infant safety, provides information on HALO SleepSacks, links to other SIDS and pregnancy and parenting websites, provides information on the Cribs for Kids Project, Stop Smoking Stop SIDS, SIDS Risk Reduction education, and information on SIDS Mid-Atlantic events.

Bereavement Training

SIDS Mid-Atlantic partnered with RTS Bereavement Services and Prince William Hospital to provide a two day training "Grief and Loss in Pregnancy and the First Year of Life" for health care professionals and counselors. 25 people attended this training and received certification as bereavement counselors.

Family Support Events

SIDS Mid-Atlantic holds an annual "Celebration of Remembrance", providing an opportunity for SIDS families to meet and talk with others who have experienced the tragedy of infant loss. Siblings and other

family members and friends also benefit from these gatherings as they offer a special outlet to express their feelings. The 2009 Celebration of Remembrance took place November 8 at the Unitarian Universalist Church of Arlington. Brisan's Bash and other family events also provide opportunities for families to support one another.

Public Outreach / Education

In 1992 the American Academy of Pediatrics identified several risk factors for SIDS and began recommending that all healthy newborns be placed on their backs to sleep. The national "Back to Sleep" education campaign began in 1994 to alert the public and professionals about these potentially lifesaving risk factors. SIDS Mid-Atlantic actively participates in the "Back to Sleep" campaign and provides information on the risk factors for SIDS through its training programs for new parents and other caregivers, childcare providers, medical professionals and the general public.

SIDS Mid-Atlantic participates in Fetal Infant Mortality Reviews, The Maryland/National Capital March of Dimes Professional Advisory Committee, the Virginia Division of Injury and Violence Prevention Community Action Group, and the Virginia Governor's Commission on Infant Mortality.

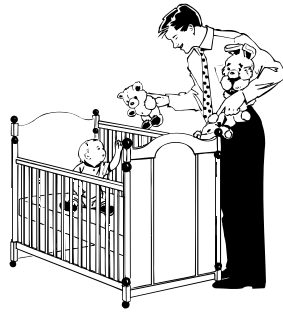
As a member of the Virginia Division of Injury Prevention Community Action Group, SIDS Mid-Atlantic participated in providing 4000 HALO SleepSacks to low income families throughout Virginia, distributing them to families at car seat safety checkpoints.



SIDS Mid-Atlantic provides education to health professionals, child care providers, first responders and families on a variety of topics including:

- Reducing the Risk of SIDS
- When a Baby Dies
- Sudden Infant Death for Emergency Personnel
- Reducing the Risk of SIDS in Child Care
- Keys to a Healthy Baby
- Safe Sleep for Your Baby
- Reducing the Risk of SIDS for Premature Infants
- Infant Safety
- Shaken Baby Syndrome
- Prematurity: It's a Bigger Problem Than You Think
- Nurses and SIDS Risk Reduction
- The Five A's Method of Smoking Cessation
- Perinatal Substance Abuse
- Infant Development in the First Year of Life
- Loss and Grieving in Pregnancy and the First Year of Life
- Perinatal Depression
- and other topics related to infant health and safety

Cribs for Kids



Each year, over 4500 babies in the United States died of Sudden Unexplained Infant Death and Sudden Infant Death Syndrome. Many of these babies did not have a safe place to sleep. Their cribs were either old and not fit for use, or they had no cribs and were sleeping on a couch or an adult bed. More infants die of accidental suffocation than die in automobile accidents. We have worked hard to ensure that all babies have safe car seats. Now we need to ensure that every baby has a safe place to sleep.

Suffocation is the leading cause of unintentional injury for children under one year of age. Nationwide, over 10,000 babies are injured seriously enough in unsafe cribs every year to require hospital treatment. Virginia's Child Fatality Task Force stated in its publication: "Unintentional Injury Deaths Among Children Age Four and Younger" "The majority of suffocation deaths were to infants and in every case the child's death was related to sleeping arrangements. The team concluded that effective interventions to prevent further injury and death must include public education messages about safe sleeping practices for infants and campaigns to provide safe cribs for families who cannot afford them."

In 2005, in the report from the Virginia State Child Fatality Review Team, "Review of Caretaker Homicide and Undetermined child Death and an Overview of Child Death in Virginia" 23 cases of deaths due to unsafe sleeping situations for infants were reviewed. Again in this report, recommendations were made that identified the need for providing cribs and education regarding safe sleep for infants to new parents.

The Child Fatality Review Team determined that the majority of these children's deaths were definitely or probably preventable. Many of the families who lost a child reported that they were unable to afford a crib for their child. As a recommendation, to prevent these unnecessary deaths, the report states: "Partnerships between public and private organizations should be cultivated for the purpose of child safety and protection. For instance, the State Child Fatality Review Team supports efforts like the "Cribs for Kids" program...of SIDS Mid-Atlantic. Cribs for Kids provides cribs to qualifying families and educates parents about age appropriate safe sleeping practices."

Since October 2003, SIDS Mid-Atlantic has donated over 6000 cribs to needy families in Washington D.C., Virginia and Maryland. To date, no family who received a crib from this project has suffered an infant death.

Some examples of the needy families who have received cribs from us include the following.

From Early Head Start in Arlington, Virginia:

"I am writing to request another crib for an indigent family. The mother is a recent immigrant with a two week old daughter. I visited her today, and she and her underemployed husband share a rented room in an apartment with two other families. They have minimal furniture, and barely cover the costs on basic needs: food, clothing, and rent. Their daughter currently sleeps in the double mattress on the floor with her parents."

From Mary's Center in Washington D.C.

“One of the mothers in our program who needs a crib is 17 years old and her baby is 2 months old. Currently the baby sleeps with his mother on a mattress on the floor. The mother is unemployed and has no income. Her boyfriend was deported to Guatemala and cannot come back to the USA. She is living with her boyfriend's brother but he has stated that he cannot continue to help her financially. She cannot afford to buy her baby a crib and would greatly appreciate your help.”

“A mother in our program is in need of a crib. Her baby is one month old. The mother is in an abusive relationship with her boyfriend. She is currently unemployed and her boyfriend makes little money. Currently the baby sleeps on a mattress with his parents. She does not have the funds to purchase a crib and would greatly appreciate your help.”

“A mother in our program is in need of a crib for her eight-month-old baby. She has a very unsteady living situation. During the time she has been in our program she has moved seven times. This is due to the fact that she cannot afford to pay rent and therefore stays for as long as people will have her and her baby in their apartments. The baby sleeps with her mother on a mattress on the floor. She cannot afford to buy her baby a crib and would greatly appreciate your help.”

From a Healthy Families support worker in Virginia

“The mother is 19 and the baby is 6 months old. The baby was born 2 months premature. The mother does not receive much support from her family, and her father recently died. I have been working with this mother and the baby. I have been trying to help with some goals. I have talked to her about college; there is a program here that offers free education. The mother lives on her own, she receives TANF and food stamps. The baby is on Medicaid. I help her with diapers and provide emotional support. I donate books to the program to help encourage our girls to read to their babies. Yesterday I asked this mother about her goals. She simply stated that she just wanted a bed for her baby.”

From the Prince Georges County Maryland Health Dept

“Just wanted to let you know I recently gave 2 cribs away. The 1st one went to a newly diagnosed HIV positive mom that lived with friends. She was going to have the baby sleep with her do to limited space. The compact bed provided by your program has given this high risk newborn a safe place to sleep.”

“The second crib was given to a mom who was going to give the baby up for adoption, but changed her mind after delivery. This mom had no baby supplies for the baby and was going to have the baby sleep with her and her 2 year old. Once again due to your program another baby has been given a safe bed.”

“Cribs for Kids” provides needy families with the most basic of needs for their babies: cribs and bedding to help prevent unnecessary and tragic infant deaths.

The “Cribs for Kids” Project addresses specific situations dealing with socio-economic issues such as crib affordability and cultural practices such as co-sleeping and breastfeeding; and parenting skills such as smoking and appropriate childcare. “Cribs for Kids” is true hands on program designed to provide both an appropriate sleeping environment—a crib—and education regarding safe sleep for babies to the families who most need the information. “Cribs for Kids” can be implemented in homes, daycare centers, churches, community centers, schools and hospitals; and involve local civic, service and social groups in the project.

SIDS Mid-Atlantic's goal in the “Cribs for Kids” Project is to eliminate tragic infant deaths that could be prevented if every baby had a safe place to sleep.

SIDS Mid-Atlantic received a community service award from the Unicare Health Plan of Virginia for its “Cribs for Kids” Project and an “Innovative Project Award” from the Virginia Department of Health Division of Injury and Violence Prevention.



“Stop Smoking Stop SIDS”

If all pregnant women in the United States stopped smoking, there would be an estimated 10 percent reduction in infant deaths, according to the U.S. Public Health Service. Currently, about 12 percent of women in the United States smoke during pregnancy.

Babies whose mothers smoked during pregnancy are four times as likely to die from Sudden Infant Death Syndrome (SIDS) as babies of nonsmokers. Babies who are exposed to their parents’ cigarette smoke after birth are twice as likely to die of SIDS.

Smoking affects pregnancy in many ways in addition to increasing the risk of SIDS, including prematurity, low birth weight, and respiratory problems in the baby. The March of Dimes recommends that women stop smoking before they become pregnant and remain smoke-free throughout pregnancy and after the baby is born. A woman’s health care provider can refer her to a smoking cessation program that is right for her, or suggest other ways to help her quit. Even later in pregnancy, a woman can reduce the risks to her baby by stopping smoking. The fewer cigarettes a woman smokes, the less likely her baby will be born with smoking-related problems.



SIDS Mid-Atlantic trains health care providers. in proven smoking cessation techniques. Smoking cessation programs can be offered at prenatal and postpartum visits to the clinics, with further support provided by home visitors from the Resource Mothers, Healthy Families and Healthy Start prenatal care programs, as well as the SIDS Mid-Atlantic health educator.

SIDS Mid-Atlantic offers pregnant and parenting women the opportunity to receive smoking cessation counseling targeted specifically to them. Many substance abuse programs, including smoking cessation, are targeted to men and/or to a population suffering from cardiovascular diseases. “Stop Smoking Stop SIDS” is tailored to the pregnant and parenting woman to meet her needs. Individualized counseling is available to women who may not be able to attend counseling during the time of their prenatal visits, and will enable the prenatal staff and the tobacco counselor to reinforce the no smoking message.

Stopping smoking is one of the few preventive measures likely to have a substantial impact on pregnancy outcome, and pregnancy is a good time to intervene since most mothers want to have a healthy pregnancy

and baby. There is also strong social pressure to not smoke when pregnant, and family and friends are more likely to support efforts to quit. Recent studies estimate that 10% of infant deaths in the United States are attributable to mothers' smoking. "Stop Smoking Stop SIDS" aims to reduce the number of smoking pregnant women and infant deaths.

Child Care Training

Two thirds of infants in the United States younger than one year of age are in non-parental childcare.

Statistically, fewer than 9% of SIDS deaths should occur in childcare. However, 18% of SIDS deaths occur in regulated childcare.

SIDS Mid-Atlantic is a recognized trainer in the American Academy of Pediatrics "Reducing the Risk of Child Care" education program for childcare providers. SIDS Mid-Atlantic trains childcare providers on techniques to reduce the risk of babies dying of SIDS, and trained 256 child care health consultants and child care providers in 2009.

Participation in Fetal Infant Mortality Review Programs

SIDS Mid-Atlantic is a member of the Fetal Infant Mortality Review committees in Virginia, Maryland, and Washington, D.C.

Donors

SIDS Mid-Atlantic is grateful to our donors and funders including:

- Anthem/Wellpoint Foundation
- BJ Foundation
- Todd Brighton
- CareFirst Blue Cross Blue Shield
- CJ Foundation for SIDS
- Sallie Eissler
- Exxon Mobil Foundation
- Heinemann Foundation
- Perry Higgs
- Maryland/National Capital Area Chapter March of Dimes
- Mary Morton Parsons Foundation
- Ronald McDonald House Charities
- Safeway Foundation
- Alexander and Margaret Stewart Trust
- The Springer Family
- TJX Foundation
- Venable Foundation
- Virginia Division of Injury Prevention
- Virginia Chapter March of Dimes

- Wawa Foods
- Washington Forrest Foundation
- Washington Post Foundation
- Weissberg Foundation
- Scott Wilkinson
- The Family and Friends of Kylie Xiu Clifford
- The Family and Friends of Christopher Hanks
- The Family of Lily Heavey
- The Family of Colin Knowles
- The Family and Friends of Brenna Mullaley
- Brian Rainey
- Steve and Katie Scully
- The Family of Armani Spady
- The Family and Friends of Brisan Winner
- Jill Wood
- The Family of Hayley Wood

Brisan's Bash in memory of Brisan Winner September 19 2009

Michelle and Paul Winner hosted the fourth annual Brisan's Bash, to honor their son Brisan who died of SIDS September 28, 2004.

Michelle has created tee shirts, bumper stickers and other items with the logo she designed, to help fund our programs and to keep Brisan, and all of our babies, in our hearts, forever.

This year's theme was "Stomp Out SIDS" and the event took place at the beautiful Philip Carter Winery in Hume Virginia.



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for Brisan - 6/01/04 - 9/28/04



SIDS Mid-Atlantic 2009 Annual Financial Report

Statement of Revenue

1. Contributions, gifts, grants, fees and similar revenue received	
a. Direct public support	\$102,596
b. All other revenue	\$5020
2. Total Revenue	\$107,616

Statement of Expenses

3. Administrative, fundraising, program and other expenses	
a. Program service expenses	\$128,735
b. Management and administrative expenses	\$7165
c. Fundraising expenses	\$1200
d. Other expenses	\$0
4. Total Expenses	\$137,100

Administrative/fundraising expenses as Percentage of Revenue **7.7%**

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SIDS Mid-Atlantic Services 2009

Support group meetings

Support groups for those affected by the loss of an infant are held the first Thursday of every month from 7 to 9 pm at McLean Presbyterian Church, 1020 Balls Hill Road, McLean, VA

- The support groups are open to any family member, friend, or child care provider who is suffering from the loss of a baby. There is no charge for any support group.
- **12 support group meetings were held in 2009.**

Peer Support

- In addition to support groups, SIDS Mid-Atlantic provides one on one peer support to families who have lost babies from parents who have suffered similar losses. Peer support is provided in the homes of families whose babies have died, in Northern Virginia, Washington, D.C. and Maryland.

Holiday Memorial Service

- SIDS Mid-Atlantic offers a memorial service to families whose babies died. In 2009, the memorial was held on November 8 at the Unitarian Church in Arlington, Virginia.
- **66 individuals attended this “Celebration of Remembrance.”**

Cribs for Kids

- Many babies die of SIDS or suffocation because they do not have a safe place to sleep. SIDS Mid-Atlantic provides cribs for needy families.
- **904 cribs were donated to needy families in 2009.**

Education Programs

SIDS Mid-Atlantic provided **60** education programs on infant safety, bereavement, smoking cessation and SIDS risk reduction, to families, grandparents, child care providers and health professionals in 2009.

Grand total: SIDS Mid-Atlantic provided 60 educational programs to 4760 people in 2009, provided 904 cribs to needy families, and provided support services to 174 bereaved families.